



Royal Berkshire
NHS Foundation Trust

Non-Invasive Prenatal Testing (NIPT) R445:

Offer for women with a previous pregnancy with Down's syndrome, Edwards' syndrome or Patau's syndrome

Information for parents

This information has been developed by NHS England R445 Working Group to provide information to service users who have had a previous pregnancy with a positive result for Down's, Edwards' or Patau's syndromes (T21, T18 and T13)

What are my testing options if I have previously had a pregnancy or child with Down's syndrome, Edwards' or Patau's syndrome?

We understand that you might need different information for your current pregnancy when you have previously had a baby with Down's syndrome (also known as Trisomy 21 or T21), Edwards' syndrome (Trisomy 18 or T18) or Patau's syndrome (Trisomy 13 or T13). This leaflet will outline the screening and diagnostic testing options available to you.

The word 'baby' is used in this leaflet as feedback from parents tells us that this is the most acceptable word. We are aware that some people won't find this appropriate so we are sorry if it causes you any distress.

Screening tests for Down's syndrome, Edwards' syndrome and Patau's syndrome

All eligible women are offered the choice of screening tests to work out the chance of their baby having one of these conditions. These tests are known as either the Combined test or Quadruple test depending on how many weeks pregnant you are. They involve a sample of blood from the arm to check specific hormone levels and an ultrasound scan to get measurements from the baby.

Further information about the screening tests, Down's syndrome, Edwards' syndrome and Patau's syndrome can be found in "Screening Tests for you and your baby" leaflet provided by your healthcare professional and available online here

<https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby>.

You are offered a different pathway to the combined test or quadruple test as you have had a previous baby with one of these conditions.

Your testing options

There are three options available to you.

1. **No testing:** If you decide not to have any testing, you will still be offered all other parts of your routine antenatal care. Your midwife will explain what this means for you.

If you have any questions/concerns, please contact your healthcare provider. For example, obstetrician (doctor for pregnancy) or midwife.

2. **Non-Invasive Prenatal Testing (NIPT):** Non-invasive prenatal testing (NIPT) is a screening test which is more accurate than the Combined or Quadruple test. This test involves measuring the DNA (genetic material) in your blood by taking a blood sample from your arm. It is completely safe and will not harm the baby.

Most women will get their result within two weeks of having NIPT, however you should be contacted if there are any delays. It is important to remember that NIPT is still a screening test. The result will be reported as either 'higher-chance' or 'lower-chance' for the conditions screened for. In a small number of cases, it won't be possible to give a result.

3. **An invasive diagnostic test:** Invasive diagnostic testing involves taking a sample from the placenta (chorionic villus sample - CVS) or amniotic fluid (amniocentesis). The chance of miscarriage from either of these tests is around 0.5% (1 in 200). It usually takes 2-3 days to get a result that can tell you if your baby does or does not have Down's syndrome, Edwards' syndrome or Patau's syndrome.

Which, if any, testing to have in your pregnancy is a personal decision. Your healthcare team will support you whatever you decide.

If you would like any further details on any part of this leaflet, please ask your healthcare professional.

Please be aware that this is general information and options outlined may not be suitable for all parents with a previous child with Down's syndrome, Edwards' syndrome or Patau's syndrome.

Always discuss options with your healthcare provider.

Useful support organisations and links

1. <https://www.downs-syndrome.org.uk/>
2. <https://www.soft.org.uk/>
3. <https://www.arc-uk.org/>

Named Midwife/Team	Antenatal and Newborn Screening
Contact Tel:	07768 850609
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To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

A McMaster, PM ANNB Screening, April 2024

Next review due: April 2026